

# Using a 'collaborative contextual enquiry' methodology for understanding inclusion for autistic pupils in Palestine

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DOI:

[10.1080/00131911.2017.1358153](https://doi.org/10.1080/00131911.2017.1358153)

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*Citation for published version (Harvard):*

Ashbee, E & Guldberg, K 2017, 'Using a 'collaborative contextual enquiry' methodology for understanding inclusion for autistic pupils in Palestine', *Educational Review*, pp. 1-19.

<https://doi.org/10.1080/00131911.2017.1358153>

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**Title:** Using a “collaborative contextual enquiry” methodology for understanding inclusion for autistic pupils in Palestine.

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**Acknowledgements:**

Our study owes an enormous debt of gratitude to staff at the Qattan Centre for Educational Research and Development (QCERD) – A.M.Qattan Foundation in Ramallah, whose constant support made the research possible. Rasha Mesleh, appointed by QCERD as assistant and translator gave invaluable support with fieldwork and data collection. We give particular thanks to the teachers, parents, practitioners at the Friends School in Ramallah and the Amira Basma Centre in East Jerusalem, and to staff at the special needs department of the Ministry of Education, as well as the many Inclusive Education Counsellors who participated in the research. In addition we are indebted to staff at the centres of community provision who took part. They include Annahda Women’s Centre, the Friends of Autistic Children Society, Star Mountain Centre, Tulkarem Rehabilitation Centre, the Jerusalem Autistic Child Care Organisation and the Terre des Hommes inclusion project in East Jerusalem. Also we are grateful for the contributions of staff at Ahliya University in Bethlehem and An-Najah University in Nablus.

## **Abstract**

This study investigated conceptions of inclusive education for pupils with autism in the West Bank and East Jerusalem, Palestine. The “contextual collaborative enquiry” methodology was rooted in praxis, and drew on social learning theory and communities of practice to gather a community of researchers, parents and practitioners in Palestine to investigate understandings of autism educational practice in order to identify how to move practice forward. Through mixed methods, we interviewed a purposive sample of key people (n=19) to gain access to a broad range of perspectives on the research topic; visited Centres of provision for children with special needs (n=6) and other specialist settings (n=8), and ran a two-day interactive and dialogic workshop with staff (n=40) from the special needs department of the Ministry of Education. Through a rigorous Interpretative Phenomenological Analysis of interviews, field notes, questionnaires and focus groups, we found that the biggest obstacles to inclusion were stigma, lack of knowledge and poor diagnostic practices, coupled with a rigid education system and an absence of shared understanding of what inclusion might mean for Palestine. There were gaps between beliefs in social justice and the concrete reality of including children with autism. Despite obstacles and barriers to inclusion, participants were passionate about gaining new knowledge, adopting different pedagogies and enabling inclusion. These findings are significant as they highlight that a push towards more inclusive practices through social learning approaches could be a powerful driver in mounting a challenge to the inflexibility within the current education system in Palestine.

**Key words:** inclusion; autism; inclusive education; Palestine; collaborative methodology.

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### **Abstract**

This study investigated conceptions of inclusive education for pupils with autism in the West Bank and East Jerusalem, Palestine. The “contextual collaborative enquiry” methodology was rooted in praxis, and drew on social learning theory and communities of practice to gather a community of researchers, parents and practitioners in Palestine to investigate understandings of autism educational practice in order to identify how to move practice forward. Through mixed methods, we interviewed a purposive sample of key people (n=19) to gain access to a broad range of perspectives on the research topic; visited Centres of provision for children with special needs (n=6) and other specialist settings (n=8), and ran a two-day interactive and dialogic workshop with staff (n=40) from the special needs department of the Ministry of Education. Through a rigorous Interpretative Phenomenological Analysis of interviews, field notes, questionnaires and focus groups, we found that the biggest obstacles to inclusion were stigma, lack of knowledge and poor diagnostic practices, coupled with a rigid education system and an absence of shared understanding of what inclusion might mean for Palestine. There were gaps between beliefs in social justice and the concrete reality of including children with autism. Despite obstacles and barriers to inclusion, participants were passionate about gaining new knowledge, adopting different pedagogies and enabling inclusion. These findings are significant as they highlight that a push towards more inclusive practices through social learning approaches could be a powerful driver in mounting a challenge to the inflexibility within the current education system in Palestine.

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### **Introduction**

Although inclusive education (IE) has been championed with increasing force since the international Salamanca agreement of 1994, ideas on inclusion have historically moved uncritically from north to south (Miles, 2002) and developing countries have sometimes expensively copied inappropriate models from the west leading to the introduction of approaches which are alien to the culture into which they are imported (Thomas, 2013; Kisanji, 1998; Closs, 2003). In addition, foreign aid to developing countries can impose alien agendas bringing negative outcomes (Nes, 2003). In the worldwide trend towards inclusion

(Farrell and Ainscow, 2002; Thomas and Vaughan, 2004), inclusive education therefore needs to become a process of “people enquiring into their own context to see how it can be developed” (Clough and Corbett, 2000:39), indicating potential for each region to contribute new approaches arising from their unique experiences and perceptions. Understandings of inclusion can be enhanced by research into perspectives from across the world, including from countries with different cultures and economies (Booth and Ainscow, 1998), through working together across national boundaries (Allan, 2008). In this process, it matters that countries find their own route towards IE as each varies in its history and culture (Mittler, 2003; Malki, 1997) whilst recognising that it is quite possible that parts of the developing world can stand as exemplars to the north (Thomas, 2013). A diversity of perspectives on inclusion can be a stimulus for new thinking about inclusion through looking at and working with other cultures in a way that can help clarify what we mean by inclusive education (Corbett, 2000).

This is by no means an uncomplicated process, as highlighted by Allan (2008), who suggests that we need to “complicate rather than explicate” (p156); in other words, we need to understand the messy complexities of inclusion rather than simply accept the concept on a superficial level. Allan’s concept of “interstanding” is particularly apt here as it is about seeking meaning and shared understanding through a dialectical approach of trying to understand each other’s realities and come to shared understandings of inclusive practices, whilst also keeping in mind that policy makers and practitioners are not always talking about the same thing (Watkins and D’Alessio, 2009). There is therefore a need to move beyond a conception of inclusion as an abstract, general and broad concept by examining policies and practices at different levels of granularity, whether those are at national, school (policies, practices, support structures) or individual level (differentiation, universal design, individual education plan) (ARACY, 2013), highlighting that inclusion should be approached as a dynamic and evolving *process* in which different factors interrelate in a complex way. Such an international reciprocal sharing of perspectives can become a foundation for strengthening understandings of inclusion (Booth and Ainscow, 1998; Clough and Corbett, 2000) and provide an attractive alternative to the traditional transmission of knowledge from north to south, by building on, rather than supplanting existing culturally appropriate knowledge (Wenger, 2009).

This process of sharing, developing and harnessing knowledge and practice has the potential to be instructive in circumstances such as Palestine where complex geographical

fragmentation (Nicolai, 2007) make this challenging. Progress has been made towards inclusion in Palestine (NAD, 2010) but on-going constraints include traditional inflexible teaching methods, a demanding curriculum and lack of funding as well as a lack of a shared concept of what IE means for Palestine. Despite evidence of negative attitudes towards people who are disabled or different (Zayed, 2014; Al-Thani, 2006), Palestine has a growing awareness and acceptance of disability rights (Jarar, 2014); it was a signatory to the Salamanca agreement (UNESCO, 1994), and Palestinian law enshrines the right of children with disabilities to an appropriate education (Palestinian National Authority, 1999). Many children with disabilities in Palestine nevertheless still miss out on education (Farrell, 2007) and there is a mixed picture in terms of attitudes towards inclusion. Despite finding that attitudes were changing, Lifshitz (2004), for example, found established approaches to teaching in Palestine tended to see children with disabilities as obstructing the important task of education to the detriment of society as a whole. On the other hand, Opdal et al. (2001) found that 60% of teachers in their study believed that children with SEN should have the opportunity to attend mainstream schools, with 90% stating public schools should change to meet the needs of children with SEN and disabilities.

Meanwhile, consideration of the educational needs of children with autism is a recently identified issue in Palestine (Ashbee, 2016). Dababnah and Parish (2013) describe a toxic mixture of stress, shame and blame that is the experience of many parents of children with autism in Palestine. Diagnosis of autism is uncommon and unreliable in Palestine although evidence from the literature does not indicate that Palestine is likely to be any different from other parts of the world in terms of prevalence (Ben-Sasson, 2012; Daley, 2002; Elsabbagh, 2012) where estimates range from one in a hundred (Baird et al., 2006) to one in sixty eight (Centre for Disease Control and Prevention, 2014). The complex nature of autism demands knowledge, adaptability and flexibility and by understanding inclusion for pupils with autism it has been posited that we can become better at understanding inclusion for all (Guldborg, 2010). Furthermore, teachers in inclusive settings are likely to come across children with autism, and as Palestine's education strategists aim for inclusion, teachers there need to know about autism. However, just as there is a need to avoid a "one-size-fits all" approach in thinking about the education of children with autism, so too in thinking about models for inclusion there is a need for a diversity of approaches and local, culturally appropriate solutions are needed. This study considers these issues in the context of Palestine.

It is important to understand something of the geopolitical context which forms the backdrop for our study. Palestine sits in a geographical crucible of three of the world's major religions, Islam, Christianity and Judaism, and also has a vibrant secular population. However, fifty years of Israeli occupation have led to stagnation and geographical fragmentation for Palestine. The Israeli occupation, some prefer the term 'colonisation' (Pappé, 2014), profoundly impacts on daily life in Palestine. International and Palestinian voices tell of the commonplace experience of oppression (Chomsky, 2010; Pappé, 2006a; Pappé, 2006b; Baroud, 2013; Nabulsi, 2014); the loss of Palestinian homeland (Pappé, 2006a); the suffering of Palestinian children (Unicef, 2010; Pilger, 1991); the lack of freedom of movement for Palestinians (Fleishman 2014; Barghoutti 2004; Howell, 2007; Tutu, 2014); the contravention of international law by the Israelis (Pappé, 2010 and 2006; Said, 1979; Pilger, 2002; Tutu, 2014); and an international disregard for the suffering and lack of self-determination of Palestinians (Said, 1979). Despite this, Palestinians are considered to be one of the most educated peoples within the Arab world (Pappé, 2006) and education is highly valued by the Palestinian people (ibid) as they struggle for self-determination.

### **Aims, research questions and methodology**

The aims of this paper are to provide a rich understanding of inclusion for autistic pupils in Palestine by investigating current understandings, knowledge and practice in relation to children with autism. The overarching research question was *“what are the barriers to inclusion and what opportunities can be found to develop inclusive educational practice and provision for children with autism in Palestine?”*

The methodology focused on gathering a community of researchers, practitioners and parents in Palestine to build a nuanced picture of the evidence base, using the lenses of both of research and practice to meet our aims. The importance of multiple perspectives is well documented in the literature on autism practice (Charman et al., 2011; NIASA, 2003; Parsons et al., 2009) and we wished to understand the views, perspectives and experiences of those who engage directly in practice and provision, with a particular focus on investigating their views on the structural barriers they were facing in their day-to-day practice. We used “communities of practice” as a theoretical and conceptual framework for our methodological approach, examining how meaning about the domain of “good autism practice” develops through a dynamic and dialectic process and recognising that this on-going process involves constant dynamic change within complex, historically defined boundaries. Our unique “contextual, collaborative enquiry” methodology entailed working in close partnership with

the Qattan Centre for Educational Research and Development (QCERD) – A.M. Qattan Foundation, an independent Palestinian research institution, whose mission it is to assist Palestinian teachers in acquiring new skills and improving their knowledge. QCERD cooperates with the Ministry of education, NGOs and the Palestinian universities to empower Palestinian teachers and to provide teachers with the opportunity to become researchers. QCERD were involved and engaged in the research at all levels, provided a translator throughout the research and also translated the research report to Arabic. Ethical approval was gained through the robust ethical approval processes in place at the lead institution, and a legal contract was signed between the lead institution and QCERD to ensure that both organisations adhered to the same ethical approach, and to the secure management and storage of data.

Fundamental to the values of the research was the endeavour to capture the voice of people in Palestine, and to understand their realities. The history of the Palestinian people is characterised by a lack of concern for Palestinian voices. Palestinians are still excluded from the discourse relating to them (Baroud, 2014) and educational researchers have called for Palestinian teachers to be producers of knowledge (QCERD, 2014), rather than mere passive recipients of western ideas and handouts (Khaldi and Wahbeh, 2002). The research was therefore not only grounded in giving attention to the voices, perceptions, rights, and wishes of the partners and participants in the research, but also in ensuring that participants engaged in the research endeavour as collaborative partners and as “experiential experts on the subject” (Smith and Osborne, 2008: 59). This included involving participants in creating a vision for how Palestinian society can move forward in improving educational practice for pupils with autism.

### **Sampling and data**

Our research focused on the West Bank and East Jerusalem for practical and logistical reasons. We worked with a cross section of individuals from the West Bank and East Jerusalem. We interviewed a purposive sample of key people (n=19) to gain access to a broad range of perspectives on the research topic; gathered field notes and observations from visits to Centres of provision for children with special needs (n=6) as well as to other specialists (n=8) and we ran a two-day interactive and dialogic workshop with staff (n=40) from the special needs department of the Ministry of Education. The purpose of the *interviews and fieldwork* observations was to gain an overall contextual insight into autism practice and understanding in Palestine. The *workshop with the Ministry of Education* staff was a



methodological tool for assessing current knowledge and educational practice on autism through engaging and collaborating with those who are in a position to lead change in Palestine. The *interviews* consisted of parents (6); teachers (5); practitioners (2); community providers for children with special needs (3); Ministry of Education staff (2) and one University researcher. Although there were issues with the extent to which this sample was representative (we note here that the sample of parent interviewees was atypical as all had educational placements for their children whereas many do not), the sample nevertheless represented people whose perspectives could provide insights into barriers, possibilities and potential ways forward. The interviews were complemented by visits to a key specialist centres in Ramallah, Jerusalem, Surda, Tulkarem and Al Bireh (6 in total); Schools (3); the Inclusive Education Project in East Jerusalem; Universities (2); a conference on autism (Bethlehem); and workshops and discussions with teachers at QCERD.

Participants at the workshop (40) were Inclusive Education Counsellors (IECs), Resource Centre professionals (occupational and physiotherapists, speech therapists, special education and social workers) and Education Supervisors. We selected the participants in this workshop on the basis that they acted as representative of the “landscape of practices” in autism education. In developing theories around social leadership and landscapes of practice, Wenger-Trayner et al. (2014) describe competence as something defined by a community. We were interested in how this competence was perceived by key stakeholders in the community in Palestine. Given that legitimacy in that community is part of “what makes someone a trustworthy practitioner” (p3), it was important for us to select people whose “experience in providing a service reflects the current competence of a community” (p3). Our justification for this was that they have the potential not only to influence the discourse of the community, but to shape access to resources.

A significant limitation of this study is that we were unable to identify autistic adults in Palestine to be included as participants. Neither were autistic children included, as our enquiries about this led us to conclude that for children prone to anxiety, unsettled by change and unskilled in social interaction, trying to converse through a translator with a foreign researcher would be a step too far for them.

The collaborative contextual enquiry, described here, formed the first phase of our research project. A second phase of action research in two progressive Palestinian schools enriched

and strengthened the study and is alluded to briefly in the forward-looking conclusion to this paper.

## **Findings**

### **The context: findings from Interviews and field observations**

Given the focus on understanding the context of autism education from the vantage point of different perspectives, our analytical approach to the interviews and field notes used Interpretative Phenomenological Analysis (IPA) as a tool to help us interpret the meanings of participants and to understand more about their lived realities. Each of the 19 interview recordings was transcribed verbatim into Word documents, placing timings in a left hand column to aid retrieval of data. An iterative review of the scripts, using Word comment boxes to annotate key points, enabled the identification of emergent themes. The interview data were put into six groups according to the role of the interviewee (parents, teachers, etc.) and the key points from the comment boxes were then collated into a six role-specific documents. These represented the emergent themes. Further scrutiny enabled the first author to cluster emergent themes and to identify five dominant themes (see Table 1) drawn from the data (Smith et al., 2009). Codes (A to E) were allocated to each of these five dominant themes and a combined table of data was collated for each. The interviews and field observations gave a clear contextual outline for autism education in Palestine, as emerging from the outlook of a number of different stakeholders, with parents having a particularly strong voice.

**Table One: The five dominant themes**

<b>The five dominant themes</b>	
A.	Inclusion
B.	Social attitudes towards autism, special needs and disability
C.	Diagnosis, autism provision and practice in Palestine
D.	The experience of parents and families
E.	Barriers to progress, opportunities and aspirations

In the ensuing discussion of each of these five themes, participants are identified by codes used in the analysis: Teachers (e.g. T1, T2); Parents: (e.g. P1, P2); Ministry staff: (e.g. M1, M1); Practitioners: (e.g. PR1, PR2); Community providers: (e.g. CP1, CP2) and University staff: (e.g. U1).

### **Theme A: Inclusion**

The notion of inclusion had strong currency and interviewees from different fields spoke fervently about the importance of inclusion, in terms of beliefs in social inclusion, equality or human rights. One teacher identified the inflexibility of education in Palestine as a huge barrier to be overcome: *“Our system of education is very, very rigid and this in itself is a big obstacle towards inclusion”* (T1). In the words of one teacher *“every student should have rights. He should learn in the society. I believe in social equality”* (T4). Parents spoke passionately about the importance of having their child in an inclusive setting and Ministry staff were pleased by what had been achieved towards IE, but recognised that there was still work to do. They felt hampered by a lack of clarity about inclusion. One commented that there was *“no clarity about the inclusion policy”* (M1). The question of what is meant by “inclusion” ranged from *“the way you teach”* (T1); to *“find suitable conditions for the children with special needs in order to include them in the class”* (M1) and *“every student should learn the subject he or she loves”* (T4). At times, “inclusion” and “integration” were used interchangeably, with one interviewee expressing frustration with the lack of understanding of inclusion: *“they are talking about inclusion and at the same time they are doing a classic system of integration”* (T1).

### **Theme B: Social attitudes towards autism, special needs and disability**

Despite these positive views of the notion of inclusion as an abstract term, the concrete reality of including children with autism was very different. The predominant perception in the interviews was that negative and exclusionary social attitudes towards autism, special needs and disability were widespread, illustrated here in the words of one interviewee: *“at parties like Eid they put him [the child with autism] in a room and close the door”* (CP1).

Three parents said that their families were accepting of their child, but one mother said: *“My husband’s family does not accept the child.”* (P5); another said: *“The neighbours’ children won’t play with Samar.”* (P4). One parent said that her family and neighbours *“started to say what is wrong with Mahmoud? He is stupid.”* (P6). A practitioner commented that *“people think it is a waste of money to spend it on these children”* (PR1). A leading member of the

special needs team at the Ministry had been rebuked for wanting to provide resources for “*the mentally retarded, for the idiots (M2)*”.

However, a member of staff at the Ministry of Education felt that “*there is a growing acceptance of disability and SEN. Attitudes are changing (M1)*”; and there was also the perception that “*there is more awareness of autism now in the Arab media. (T4)*”. Several interviewees spoke of the rights of people with disabilities and autism: another member of staff at the Ministry of Education asserted that “*As Palestinians we have learnt to fight for our rights and now we are fighting for the rights of people with disabilities*” (M2). In contrast, there was a view that conditions such as autism were regarded pityingly: “*We don't have a positive perspective. People in our community look at it in pity [and] more from a religious, charitable perspective, [feeling] poor parents*” (T1). One interviewee talked about the greater acceptance of physical disability, compared with other types of disability or difference: “*In Palestinian society there is no problem for people with physical disability because through the two intifadas we have many injuries so if you have a physical disability you are thought to be a hero. But with autism there is not enough awareness. People think they are mentally retarded*” (PR1).

### **Theme C: Diagnosis, autism provision and practice in Palestine**

Findings on diagnosis pointed to widespread lack of identification of autism in Palestine. One interviewee told of a mother who, concerned at her four-year-old child's lack of social interaction, consulted a paediatrician who after fifteen minutes gave her a sealed envelope and moved on to the next patient. The mother opened the envelope and read “*Your son is mentally retarded and should start a programme with us*” (U1). No further advice was offered. Two years later the boy was diagnosed with autism. Not only parents found the lack of diagnosis frustrating. A member of the special needs team at the Ministry felt that “*we first need to identify the people who have autism by reliable diagnosis*” (M1), without which there could be no provision for the child with autism. Most interviewees (13) gave the opinion that Palestine was not yet able to address the needs of children with autism. In the words of one, “*Autism is a “new area” in Palestine and is not widely understood by professionals or within society as a whole*” (M1). A lack of understanding of the breadth of the autism spectrum was raised by three people, with one saying, “*in the West Bank if you have someone with high functioning autism nobody considers him as having autism*” (PR1).

### **Theme D: The experience of parents and families.**

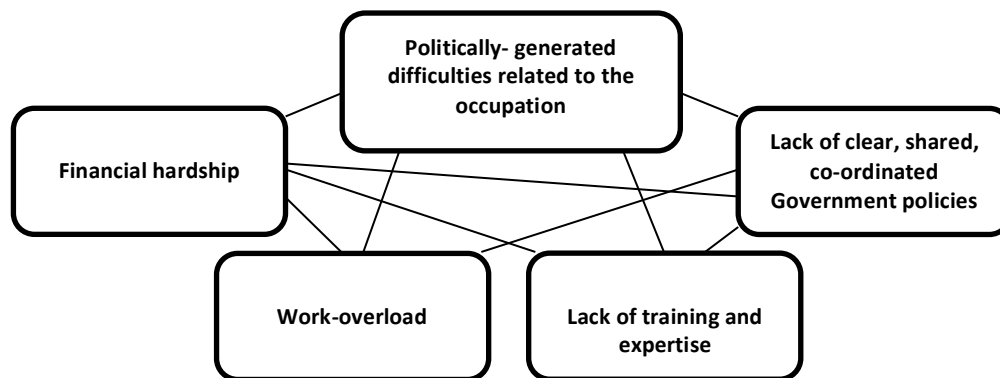
Challenges for parents and families constituted a potent theme to emerge from the interviews. Parents expressed frustration at the lack of support and understanding, lamenting that *“nobody knows about autism”* (P2), and *“the government school won’t take this child”* (P5); *“teachers do not know how to deal with autistic children (P4)”*; and *“the Palestinian curriculum is a disaster for [an autistic child]”* (P3). Four parents spoke of a negative impact on families of having a child with autism. One mother wept as she said: *“Nobody knew we were having this crisis”* (P2) and, speaking of the financial cost, said that *“It has been a lot of time, effort and money to help”* her son. Another mother experienced a lack of acceptance by family and neighbours and said: *“because of that I prefer to stay at home with Ruba all the time”* (P5). Parents touched on the impact on siblings, with one parent saying: *“his sister will take care of him when he is older”* (P5). Another impact on siblings was pointed out by an interviewee who reported that *“there is a problem if they have other children because nobody will want to marry them because this family has disability so if you marry into this family [people think] you will have a child like him”* (CP1), so the future well-being, happiness and social inclusion of siblings was also thought to be affected by the presence of autism in a family. Three parents spoke of the negative impact of the Israeli occupation on their lives. Having a baby at the time of the second intifada was an anxious experience for two mothers (P1, P2) and in one case (P2) the mother experienced dangerous difficulty in getting through the checkpoint to reach the hospital in Jerusalem when she went into labour as travel restrictions for Palestinians living in the West Bank seriously limit their ability to access facilities outside.

Parents voiced both negative and positive feelings about their child’s autism. One parent had experienced depression and said: *“I didn’t want my child to be autistic so I tried to teach her to look normal”* (P4). One mother also spoke of depression and feared for her son’s future, saying *“I am not happy because I will die and he will stay alone in his life”* (P1). Another parent spoke of a *“crisis”* in which *“I was crying all the time because all my dreams they were smashed”* (P2). However, the parents all spoke of coming to accept and love their child. *“He is amazing. He is a gift”*, said one (P3). *“I’m lucky to have him; he changed our life, he changed me for the better”*, said another (P2). A third mother said that she was *“hopeful for the future, inshallah”* (P5). So, although perplexing isolation dominated the lives of many parents our research nevertheless revealed parents had strong signs of agency. For example, P1 had sought out other parents and formed a group; P2 had scoured the internet for information.

## Theme E: Barriers and opportunities in progressing the provision for children with autism

Although barriers to progress was perhaps the *sine qua non* for all the other dominant themes, it was not obstacles that participants dwelt upon but the wish to build and look ahead. Interview data relating to barriers to making provision for children with autism fell into five broad interlinked groups (see Figure 1) and the one that linked them all was that of difficulties related to the Israeli occupation. As one of the interviewees put it: “*the whole system is the obstacle*” (T1).

**Figure One: interrelationship of barriers**



These five barriers, not distinct but closely inter-related, are summarised here. Several interviewees talked of difficulties related to the Israeli occupation: trying to set up special needs provision when travel restrictions made “*accessibility and moving around schools very difficult*” (M2); and when Palestinians “*live in a country where we have a problem every single minute – not just autism, not just poor. The occupation is a big challenge for us*” (PR1); when time and energy is wasted because “*we spend hours on the checkpoints*” (T2); and when, as well as practical frustrations there is a damaging impact on society and on children for whom “*just going through a checkpoint makes them see the violence and verbal aggression*” (T3). Data indicated a widespread lack of resources: at the Ministry where “*financial restrictions*” (M2) meant they had to shelve plans to introduce a reduced workload for “focus teachers” to enable them to have a role in supporting special needs; and at the centres in the community where “*unfortunately, no funds, we have financial problem*” (CP3). Interviewees spoke of the insecurity and instability of relying on donor funding as donors often decided to reallocate funding elsewhere so that “*projects just last for a period but*

*[then] the situation goes back to what it was” (CP1). Lack of financial resources had also limited the opportunity for Palestinians to be part of the international community, for example to attend conferences related to autism. For teachers, work overload was also an issue: “as well as a lack of training, they have 27 classes each week and feel that they do not have time to teach children with autism” (M1). For Inclusive Education Counsellors (IECs), 36 of them “cover more than 1200 schools so that workload is huge. In addition, they try to address all areas of SEN” (M1). For Ministry staff too, “overload becomes a barrier” (M2).*

Lack of training and expertise was seen as a barrier to development throughout the education system where *“Initial teacher training does not include SEN, and certainly not autism” (M1)* and IECs *“lack a thorough professional training in SEN” (M1)*. Interviewees pinpointed *“lack of specialisation” (M2)* and the fact that *“teachers are not specialist” (CP3)* as a barrier. This was because *“there are no universities in Palestine that offer courses in autism or any special needs courses” (M1)*, although there are now indications that this is changing. One interviewee felt there was a bigger problem with the preparedness of teachers for their professional role as *“teachers come with no training at all, not only in dealing with children with SEN, but in education in general. The education we have is very traditional [and] didactic. If I want to include a child on the autistic spectrum I need a lot of flexibility” (T1).*

Some commented on a lack of clear, shared Government policies. One interviewee said that *“although we have the Council for Special Education and People with Disabilities, they are not doing much” (U1)*. There were *“no clear policies” (M2)*; and *“we have disability rights laws, but we are not using them” (CP1)*. There was thought to be no clear understanding of which government department should take responsibility for autism. Centres in the communities regretted a lack of financial support from government. One said *“we bring someone important to see our work, Minister of Education, Minister of Social Affairs. They are proud of our work but they do nothing” (CP1).*

Much had been achieved that set the climate in which developments towards inclusive education for autism are more possible, but the need for training was seen as a key issue. Ministry staff said that if *“a teacher needs to teach a child with autism there must be opportunities for professional development” (M1)*. One teacher asserted the need to *“give people the skills and the confidence and the training” (T4)*. Another saw a need for *“changing the classroom environment”* and felt that *“this would help a lot of kids, not only those with autism” (T1)*. Concern for the parents of children with autism was a common

theme and several people spoke of the urgent need to support them. The benefits of working in collaboration with others to develop autism provision was an issue raised by some interviewees (n=4). Two interviewees (U1 and CP1) felt they needed opportunities to be part of a wider international group. Another interviewee (U1) said that Universities in Palestine have an important role to play in the issue of provision for autism and that as well as providing specialist courses for educational professionals their work should be connected to research should inform government strategy.

### **Findings: Ministry of Education Workshop**

Whilst the interviews were designed to give a contextual overview of the perspectives of a number of different stakeholders in the field of autism, the Ministry of Education workshops were run as interactive dialogic workshops through which we aimed to drill down more concretely into perceptions and understanding of autism through working collaboratively with a group of *leading* practitioners to identify ways forward. The Ministry of Education appoints the Inclusive Education Counsellors (IECs), whose role is to support schools to include children with SEN. As such, their involvement in the research and recommendations arising from it can be seen as pivotal. Of the 36 IECs serving the West Bank and Jerusalem at that time, 31 (78%) of them attended the workshop. The two-day workshop was organised as an interactive dialogic workshop focusing on the perceptions of this key group of Palestinian professionals by probing understanding of autism and education; discussing access to education for autistic children in Palestine; identifying the barriers to the inclusion of children with autism and exploring perceptions of opportunities for change. We were interested in knowledge about autism and knowledge about supporting a child with autism. The data we analysed drew on a questionnaire given to all participants.

After analysing the findings from questionnaires, the category of “knowledge about autism” generated codes that grouped this knowledge into “definitions”, “facts” and “features.” Taken as a whole, responses to a questionnaire indicated that in relation to definitions of autism, a medical model of autism was foremost and autism was conceptualised in terms of “*deficits*” with 43 responses to the questionnaire (some people gave more than one definition) using the words “*disability*”, “*disorder*”, “*dysfunction*”, “*illness*”, “*disease*” (see Table 2).

### **Table Two: definitions of autism**



Definitions of autism	(Number of responses indicating this category) and Sample Quotes
Disability, disorder, dysfunction	(18) <i>Disorder of the nervous system which causes loneliness (R1) (R = Respondent)</i> <i>A disease affects the child's nerves or the electrical waves in the body which cause a brain dysfunction (R16).</i>
Involves the brain/nervous system	(10) <i>A nervous disorder, the person moves a lot, makes strange noises (R11).</i>
Illness and disease	(8) <i>Psychological illness affects the children (R20).</i> <i>Maybe it is a mental disease, makes the child feel alone (R28).</i>
Psychological or emotional disorder	<i>Emotional illness (R 5).</i> <i>Psychological disease [that] affects the children (R6)</i>
Behavioural	(4) <i>Social, behaviour disorder (R 22).</i> <i>Behavioural disorder since the birth (R26).</i>
Childhood disorder (affects children only)	(13) <i>The child can't communicate with others and lives in his own world (R 35).</i>

The emphasis on lack of ability, such as “*can't communicate*” (e.g. R35) or “*can't feel happiness, or sadness*” (R1) or “*can't recognize the things around*” (R8) suggested a view of autism that consisted of deficits. Only one respondent alluded to possible strengths in autism. The responses did not indicate a shared understanding of autism and there were notable misconceptions: that people with autism are not able to feel happiness or sadness, for instance, and the more widely held misconception that people with autism are unable to communicate. “*Communication difficulties*” was the most frequently mentioned feature, given by 22 respondents (61%). Half of these (11 in all) gave answers that suggested that people with autism are unable to communicate. For example: *The child can't communicate with others* (R35).

Nine people referred to behaviours which they associated with autism, such as “*Sometimes hits himself*” (R20) and “*the person moves a lot and makes strange noises*” (R11). Twelve

participants referred to solitariness in children with autism, expressing this in terms such as “*living in their own world*” (R14), “*loneliness*” (R1, 4, 8, 9), “*alone*” (R20, 21, 28) and “*introverted*” (R23). Only one person referred to sensory differences in autism, writing: “*It affects the person’s communication, skills, play and the senses*” (R18). Three people (R1, 3, 8) said, in the words given here of one of them, a person with autism “*can’t recognize what is happening around them*” (R1), perhaps referring to difficulties with comprehending the social environment, although this was not clear. Some individual ideas included one person’s opinion that people with autism do not have feelings: “*he/she can’t feel happiness, or sadness*” (R1). Another person said that children with autism have difficulty with “*academic skills*” (R32) and another said: “*there is a difficulty in including them in schools*” (R34). Two responses cited difficulties with focus and attention (R23, 34). Many responses used language that suggested a medical bias in thinking about autism by including medical words such as “*treatment*”, “*medical*”, *rehabilitation*” (see Table 3).

**Table Three: responses using medical terminology**

<b>Responses to Prompt 2 (Things I know about supporting a child on the autism spectrum) using ‘medical’ terminology.</b>	<b>Respondent</b>
Treat and rehabilitate them.	1
The autistic children need special rehabilitation programs.	15
Give treatment by some medicine.	16
They need psychological, social and academic rehabilitation from specialists	20
Offer help like speech therapy, occupational therapy.	23
Make a treatment plan for each student.	5
Needs different specialist to help.	26
Offer a special rehabilitation programme.	29
Depend on the medical report to diagnose.	34
The autistic people need special programme rehabilitation.	35

The largest group of responses (11 in all) referred to the need for specialists. Of these, six are also included in the “medical approach” group (above) as they refer to medical specialists. The remaining five responses (Table 4) came from respondents who perhaps saw a need for specialists who were not necessarily medical.

**Table Four: responses indicating the need for specialists**

<b>Responses to Question 2 - Need for specialists</b>	<b>Respondent</b>
He needs special programs.	4
These children need special education and to use special techniques.	14
Offer special education programs.	27
Establish some foundation to help them.	28
We must collaborate with the associations that are working with the autistic children.	31

Two respondents referred to lack of capacity for supporting children with autism. One was a personal reflection: *“I can’t give help to autistic children, and I would like to know how.”* (R7). The other was a comment on Palestinian schools: *“There is no support for them especially in the governmental schools”* (R9). Several responses suggested a positive willingness to include children with autism. Five respondents referred to the issue of inclusion. Inclusive education is a key policy within the Ministry of Education and indeed all participants held roles directly related to the implementation of this policy. Four (R7, 11, 12, 23) suggested a positive attitude towards IE. For example: *“I am working now with governmental schools to support autistic children”* (R12) and *“Include these cases into schools”* (R23). A fifth respondent acknowledged the challenge of including children with autism: *“To include a child with autism in a normal class is a hard thing except for the simple kind”* (R5).

## **Discussion**

The perceptions of different stakeholders in the community regarding current realities of autism education in Palestine provide a way of determining the community's body of social knowledge. The term "knowledgeability" as coined by Wenger-Trayner et al. (2014) is defined as the complex relationships people establish with respect to a landscape of practice, which make them recognizable as reliable sources of information. Our understanding of "knowledgeability" as discussed by Wenger-Trayner et al. (2014) is aligned with the notion that "knowledgeability", rather than simply representing knowledge, actually represents the "embodied state of the living person" through participation in practice.

This concept is useful here as the findings of this research showed clear differences in the orientation and focus of different stakeholders. Perceptions of the Inclusion Education Counsellor (IEC) participants in the workshop, reflected in the language used in the answers to the questionnaire, suggested an understanding of autism oriented towards deficits, as a pathological existence, with impairments (Arduin, 2015, Wing, 1979), and with a resultant focus on what is "wrong" with the autistic person. The descriptions and terminology used to explain autism was strongly focused on how autistic people 'deviate' from the norm. This went hand in hand with a 'charity model' perspective that saw autistic people as in need of help and of being looked after. In the context of a society that has a heavy reliance on National Government Organisations (NGOs) providing relief and with a wide range of services transferred from governments to NGOs, these perspectives are perhaps not surprising.

The parents, on the other hand, used very different language to the IECs, with a stronger focus on the external environment and the attitudes and barriers of society, and less on the notion of their child as 'an impaired individual'. Their perspective seemed to have more in common with the social model of disability, which sees the difficulties of autistic people as emerging from a particular cultural and social condition (and therefore culturally relative) (Milton, 2014). Parents were more focused on how their children were treated and perceived and thus shone the lens more clearly on identifying social, cultural and institutional barriers. This also aligns with the "interactionist" or "transactional" approach, that sees autism and disability as being part of our diversity as human beings and that the difficulties arise as a result of the interaction between the person and their environment (Prizant, 2015).

Conversely, data from the interviews and visits indicated that parents were viewed as important partners. For although parents of autistic children were often isolated at home

without support, when their children attended the centres, staff there felt it important to work with the parents. Research indicates that parent involvement is advantageous for children of all ages and that there are a number of theoretical models and practical guides to guide its development (Hornby and Rafaele, 2011). Given that the Centre staff work directly with parents, they may have more acute experiential knowledge about the importance of parent partnership than the IECs. This could explain why the IECs appeared to have a very medicalised perspective that focused on the need for experts to be involved, and it might also explain why there was little mention of parents and families: there was one mention of their importance in the questionnaire.

These points highlight how conceptions of disability are situated and variable and there “is a complex dialectic of biological, psychological, cultural and socio political factors, which cannot be extricated, except with imprecision” (Shakespeare and Watson, 2002 p 24). Shakespeare and Watson (2002) acknowledge that rejection of the medical model is largely based on an opposition to defining people solely on the basis of ‘impairment’, and they argue for the need to challenge the reduction to a medical condition, whilst also challenging the negative cultural meanings. Furthermore, they argue for the need to jettison the social model of disability, and assert that we need to honestly appraise how different ‘impairments’ can have different social and individual implications. We therefore caution against taking a judgmental attitude to those who hold a ‘medical’ perspective.

This is an important point in the context of understanding inclusion in a society in which teaching in the West Bank has been criticised for its focus on the technical dimension of education (Eisner, 2005), seeing students as consumers who receive scores rather than as individuals who learn in dynamic and changing contexts (Wahbeh, 2011), thus neglecting the values of humanism (see Eisner, 2002). This view of education is situated within a national culture in which educational success is increasingly measured by global test results (Tomlinson, 2015). In an educational setting in which these drivers would make it difficult for pupils with special educational needs, one can see why both a ‘medicalised’ and a ‘charitable’ perspective/model to special educational needs might arise among those who might be leading the way in the educational endeavour.

Whilst the dichotomy between the medical and social model takes a particular form in Palestine, this dichotomy permeates the autism world internationally. Debates between therapeutic and psychological orientations to autism often clash with sociological accounts

and there is a contrast between research and practice that focus on therapy and medical intervention and participatory approaches in school settings, that are more focused on changing perceptions and removing barriers (see Guldberg, 2016 and Guldberg et al., 2017). These differences highlight the complexity of analysing socio political contexts, of the different attitudes and values that have been constructed in Palestine, and they show that views and outlooks are often influenced by a range of perspectives and do not fall into neat 'models'. In fact, change is complex, as can be seen by the fact that physical disability is viewed through the lens of a rights-based perspective in Palestine due to the associations with the intifada and physical disability being associated with fighting against oppression.

Despite the constraints of a strict hierarchal educational system and the challenges and demands of new reforms, Wahbeh et al. (2011) highlight that "teachers still consider teaching from a more humanistic, religious, passionate, emotional, and most often patriotic stance" (p 42). Notwithstanding challenges, there are signs of agency and space in the West Bank for "teachers to share, communicate and build on their own epistemic experience and practical wisdom, among their peers, as colleagues" (Wahbeh et al., 2011, p 42). The findings from interviews and visits align with the findings of Wahbeh et al. (2011), in identifying that participants are finding spaces within the system and the curriculum to voice their opinions and perspectives.

Regardless of the starting point of people's perspectives, there was a strong interest amongst participants in developing understanding and expertise in relation to autism, with heart-warming evidence of dedicated people in the communities making provision for children. Although dependency on charitable funding made their sustainability precarious and community providers would have welcomed government funding to secure and give recognition to their work, there was a strong sense of agency. Participants in the study often called for the very things that are presented in the literature as the building blocks of good autism practice: the need for knowledge and understanding (Jordan and Powell, 1995); the need for teachers and practitioners to be supported and to work together (Charman et al., 2011, Parsons et al., 2009); the need to promote empowerment and confidence of teachers (Cumine et al., 2010); the need for education that develops the whole child rather than just drilling them to acquire a set of skills (Prizant and Wetherby, 2006); the importance of environment (Jones et al., 2008); and a recognition that what would be good for an autistic child might well be good for other children (Jordan, 2005).

Wenger argues that reflection across boundaries can also be a fruitful source of inspiration and new thinking (Wenger et al. 2014) and that to be recognised as someone with “knowledgeability” depends on the depth of one’s competence in one or more core practice(s), and it also depends on one’s “knowledgeability” about other practices and significant boundaries in the landscape. The findings from this study highlight the need for “boundary crossing” between inclusion counsellors, practitioners and parents. One of the areas in which this boundary crossing could be focused, would be on the move towards more reliable diagnosis, which was identified as a significant issue for education in Palestine. The lack of identification of autism caused difficulties for teachers, for parents, for policy makers adrift in uncharted waters and for medical professionals lacking expertise to reliably diagnose autism. Whilst many in the West recognise that provision should be needs-led rather than diagnosis-led (DfES, 2002; NIASA, 2003) and diagnosis does not tell you what you need to do to educate the child, the findings from this study indicates the risk of not identifying children through accurate diagnosis is that it has led to the needs of autistic children being unmet. There is a need to diagnose and identify autism, and to do so at an early age, but this goes hand in hand with a need to understand autism and put in place approaches and school environments that enable children with autism to be included in education.

Palestine has, at present at least, limited resources and so there needs to be an emphasis on ways forward that are cost effective and within the realm of what is fiscally possible. Collaboration between professional groups, parents, communities and government departments is needed to develop education for children with autism (Charman, et al., 2011; Prizant and Whetherby, 2006; Jones, G. et al., 2008). Knowledge, practice and values need to be shared if IE is to succeed (Florian, 2008) and this needs to be done in a way that promotes “interstanding, a dialectic process of shared understanding, (Allan, 2008). Collaboration has the potential to invigorate the teaching profession (Slee, 2001) and is in line with the aspiration of some Palestinian thinkers (Wahbeh, 2011; Khaldi and Wahbeh, 2002) as a way to empower professionals and develop practice. This focus could ensure that inclusive practice could be central in challenging the current and predominant focus on the “technical dimensions” of education and therefore become a real force for change.

### **Concluding comments**

The research findings highlighted a need for collaboration to overcome the isolation of parents and the lack of knowledge sharing between those with a stake in the world of autism. A Communities of Practice model can provide an effective social forum for learning by sharing and shaping a body of knowledge and skills within a given domain of shared interest, tapping into explicit and, perhaps more significantly, tacit knowledge. It is an approach that can empower participants by valuing their existing knowledge and skills while enabling them to develop through peer-to-peer collaboration, offering an attractive alternative to the traditional transmission of knowledge from north to south, by building on, rather than supplanting existing culturally appropriate knowledge (Wenger, 2009).

There are a number of key developments that are indicative of progress in the field of autism education in the West Bank. The action-research phase of our study, referred to earlier (and the focus of a projected forthcoming publication), offered excellent examples of good and developing practice in IE for children with autism in two educational settings in Palestine: Friends School in Ramallah and Princess Basma Centre in East Jerusalem. In order to move forward further and build on this progress, Palestinians could draw on lessons from many countries in transforming schools into learning organisations in which teachers can share good practice around improving learning outcomes for pupils (Makoupoulou and Armour, 2014). Such learning communities enable interested parties to share knowledge and work together, bringing together professionals from education, health, members of the community and, importantly, parents, families and people with autism (Parsons et al., 2009; Charman et al., 2011; Jones et al., 2008). An over-arching proposal emerging from this research therefore is for a collaborative and inclusive approach towards future development, embracing multiple perspectives within a Community of Practice and to use such an approach in the development of a collaborative training programme. This stance is firmly opposed to a cultural hegemony that might seek to impose Western thinking and practices on another culture, and it also wishes to move beyond the isolation of nationalism. Rather, we look to the fertile opportunities of “interstanding” that can come from knowledge sharing across boundaries, both inter-cultural and intra-cultural. In support of the disability rights motto “nothing about us without us”, the recommendation includes the need for the voices of autistic people to be heard, the most authentic “autism specialists” being perhaps those who are themselves autistic (Milton, 2014). The “nothing about us without us” watchword also flags up the need for the Palestinians themselves to determine their own way forward in the development of IE



for children with autism as part of their contribution to landscapes of practice within the wider world.

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